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AUTHOR Heinlein, Ken B.; Campbell, Edward M.; Fortune, Jon; Severance, Don; Fortune, Barbara

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ABSTRACT

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Garry L. McKee, Ph.D., M.P.H., Director

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Additional information and copies may be obtained from:
Jon Fortune, Ed.D.
Adult Services Manager
Wyoming Developmental Disabilities Division
Herschler Building, First Floor West
122 West 25th Street
Cheyenne, WY 82002
(307) 777-7115
(307) 777-6047 (Fax)
e-mail: jfortu@state.wy.us

This Document is available in alternative format upon request.

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Ken B. Heinlein

University of Wyoming, Wyoming Institute for Disabilities, UAP

Edward M. Campbell

$E=MC^2$ Consulting Inc.

Jon Fortune

Wyoming Health Department, Developmental Disabilities Division

Don Severance

Nebraska Division of Developmental Disabilities

Barbara Fortune

University of Wyoming, Family Practice Residency

Corresponding Author's (Jon Fortune):

Phone: (307) 777-6488

Fax: (307) 777-6047

Internet: jfortu@state.wy.us

Herschler Building, 1st Floor West, Cheyenne, WY 82002

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Abstract

The changes in what people with developmental disabilities wanted and got for living and daytime settings in South Dakota and Wyoming during 1988 were compared to what they wanted and received in 2000. Although the percentage of people in their desired setting rose, there were substantial changes in the types of settings recommended over the years. Recommendations for residential and daytime settings appear to presage changes in actual practice. The numbers of people for whom large residential facilities were recommended generally declined. Conversely the recommendations for supported employment and supported living rose sharply. The barriers to people getting social and leisure activities were also analyzed. Data from the State of Nebraska were added to the analyses. Attaining residential and daytime recommendations appears also to enhance other "quality of life" measures. The 2000 results suggest few people with no social or leisure activities, in South Dakota few people reporting the lack of transportation as a barrier and fewer having no one to accompany them to activities. All of the barriers were reported as presenting identified needs for some of the people served in Wyoming. More individuals reported family contact, family visits, and identified a hobby or personal leisure activity. The Home and Community-Based Services (HCBS) expansion of services and supports had reduced some of the social barriers to community integration and independence and increased positive social activities for many of the 7,034 people served in Nebraska, South Dakota, and Wyoming. South Dakota hit a high point in the 1987 with 87% of its people getting the program they wanted and is approaching that high with the current 83% rate. Wyoming reached a new all time high of 83-90% of its people getting the program(s) they wanted in 2000. Nebraska has a very respectable 77-82% rate of people getting what they want for a program in 1999. Importantly, the moving target of choice can function within the structured limits of the three state's various provider reimbursement models that pay more dollars to support people with increased individual challenges. Hence the ever-moving target of state financial support can still help people achieve their personal visions. Carol Burnett's question, "Are we having fun yet?" is relevant to the people we serve. Effort and diligence is needed to continue to increase choices for people we serve, to reduce barriers, and to increase positive community interactions and opportunities.

Are We Having Fun Yet? Overcoming Social Barriers and Getting the Outcomes and Activities You Want With Existing Funding Sources

Recommended placements change over time and reflect changing philosophies, purses, preferences, politics and expectations. Every year, individuals with developmental disabilities in Nebraska, South Dakota, and Wyoming meet with their interdisciplinary teams to write their individual plans of care. The teams, with input from the person served, decide the day and residential program placements from the array of alternatives that are or can be made available. Those making the recommendations can be expected to reflect the current "Zeitgeist" in the field. This asserts that they should give people with developmental disabilities the opportunity to live, learn, play, and work in the most integrated and independent settings possible.

The prevailing philosophy in the field is characterized by such terms as choice, inclusion, independence, and integration. These ideas influence expectations about which placement settings are most appropriate. As barriers to community participation decrease, individuals acquire skills needed for successful participation, or expectations change about which environment best elicits these skills, team recommendations also can be expected to change. Consequently, variations in the recommendations for placement and the barriers to community participation are time sensitive.

Research of community dwellers in densely populated states like New York (Jacobson, Sersen, & Schwarz, 1984) and California (Strauss, Kastner, & Shavelle, 1998) and urban areas, e.g., Atlanta (Wilhite, Reilly, & Teaff, 1989) has been published. The records of very rural states are few. We propose to add a rural flavor to the literature by building upon the work of Campbell (1993), Heinlein (1994), and Fortune, Heinlein, and Fortune (1995). We are combining the research efforts of two very rural states - Wyoming and South Dakota - during 1988 and 2000, years for which comparable data are available. We will also add information in 1999 from Nebraska. Of particular interest are how identified barriers to community participation and present and proposed day treatment and residential placements have changed during the interval.

Literature Review

Greenspan and Cerreto (1989) skillfully argue that implementation of a positive value system that benefits the people served appropriately goes beyond well-controlled experimentation and research validation of normalization and de-institutionalization. The vision offered by Coulter (1992) depends on a commitment to the community and family. He stresses an emphasis on human relationships, person-centered programming, and recognition of real choice and control by people with disabilities. Kishi, Teelucksigh, Zollers, Park-Lee, and Meyer (1998) examine the practical challenge of increasing daily decision-making in community residences. They found that adults with mental retardation had significantly fewer opportunities

to make decisions on such matters as what to eat or wear, how to spend free time, and with whom to live. They found a need to operationalize meaningful improvements in the lives of persons with mental retardation that go beyond the appearance of the physical placement in the community.

However, the barriers to the use of generic and categorical services in the community are numerous. Problems include lack of transportation, prohibitive cost, lack of interest (Center for Independent Living of Greater Bridgeport, 1984; Heal, Bruininks, Lakin, & Hill, 1989), or lack of a construction of a community of shared values (Calvez, 1993), and are more significant as adults with developmental disabilities age (Anderson, Lakin, Hill, and Chen, 1992; Barbero, 1989). Despite age groups, these barriers are present; although people living in the community report greater satisfaction, more community integration, better use of services and improvement in adaptive behavior or in the self-help/domestic domain (Larson & Lakin, 1989).

O'Brien (1993) points out that supported living can deal creatively and individually with the complexities arising from the lives of many different people with developmental disabilities. Bruininks, Chen, Lakin, and McGrew (1992) identified eight components of personal competence and community adjustment with mental retardation living in residential facilities of six or fewer residents. In 1993, Chen, Bruininks, Lakin, and Hayden found that personal competencies were least important in distinguishing between people living in small group homes or small foster homes. They did find that differences emerged in these factors that assess community participation, family relationships, and recreational/leisure integration.

O'Neill, Brown, Gordon, Orazem, Hoffman, and Schonhorn (1990) looked at 46 clients who left an institution and entered either an Intermediate Care Facility for individuals with Mentally Retardation (ICF/MR) or group home or apartment in New York City. The people who lived in community homes showed a gain in frequency and diversity of activities adjusting for impairment and predischarge activity levels. They recommend consciously building active opportunities for the people who remain in the institution. In cases of people with fewer skills, creating special linkages, and/or intensive training can enhance opportunities. This can provide an enriched activity pattern such as adult recreational activities in physically and socially integrated contexts.

In a South Dakota study of actual and recommended placements, Campbell (1993) found fewer persons with developmental disabilities in the more restrictive residential and day treatment settings. He also found fewer people with recommendations for the more restrictive settings in 1991 than 1981. Specifically, the institutional population decreased from 655 to 389 and group home placements decreased from 801 to 650, but staffed apartments increased from 0 to 263. Placement into sheltered employment and activity centers increased from 813 to 1140 and supervised, supported and competitive employment placements increased from 25 to 375. Actual placements were changing in the direction of greatly increased integration and independence. Recommendations were changing in the same direction, but even more dramatically. Actual placements were not keeping pace with those recommendations. The percentages of people living in their

recommended settings decreased from 80% to 66% during the decade. The percentage of persons in recommended daytime settings decreased from 80% to 59%.

Zimmerman (1982) reported that Wyoming's newly emerging community service system had 207 employees and 221 residential clients who lived in 44 sites. Most of the people served reported having the program they wanted. Seven percent wanted their residential program to be improved and/or the choice of a different day program that better fit their needs. Most of the people served had mild challenges and participated in the activities of the community for leisure and recreation. On average 94% of the people served used shopping centers, restaurants, movies or concerts, attended religious services, went on walks or field trips, and had hobbies. Most visited their families (85%), had contact with friends outside the facility (79%), and attended structured day programs outside the living unit (92%). Ten percent were in competitive work situations, 30% were in sheltered work settings, and 60% were earning inconsequential paychecks in work activity settings. Some sheltered vocational programs in Wyoming expanded to successful job placements. The rehabilitation programs used a variety of funds such as the Job Training and Partnership Act (Fortune, et al. 1986) and sometimes local dollars.

However, by 1990, the description of the early community system in Zimmerman (1982) was changing dramatically. In 1990, Wyoming was sued, and in 1991, settled a class action suit (*Weston et al. v. Wyoming State Training School, et al.* C90-0004). One result of this lawsuit was a rapid downsizing of the State Training School. The *Weston* Consent Decree also specified that persons with a broad array of disabilities have the opportunities to live in community settings. Wyoming responded (Heinlein & Fortune, 1995), greatly increasing the number of persons with severe disabilities facing significant barriers to participation in community settings. Campbell, Fortune, and Heinlein (1998) identify that state funds, then HCBS waiver dollars, then ICF/MR funding have the best outcomes of integration and independence of adults with developmental disabilities in South Dakota and Wyoming when those results are adjusted by the characteristics of the people served. The disability level of the individual served was the best indicator of independence. Heinlein, et al. (1998) describe progress in South Dakota and Wyoming in hitting the moving target of program choice and finding the desired outcomes and activities.

In the national literature, choice, habilitation, and self-determination issues began to blossom during the 1990's. The pirate's flag was raised in 1990 by Bannerman, Sheldon, Sherman, and Harchik who wrestled with the balance of the rights of the people served and their habilitation by examining the rights of people with developmental disabilities to eat too many doughnuts and take a nap. With the provocative "Would I be able to ..."?, Foxx, Faw, Taylor, Davis and Fulia (1993) suggest a three-phase program of interview, preference identification, and preference availability with six adults with mental retardation leaving an institution for the community that resulted in successful learning and generalization of the obtaining of their preferences to community group homes.

With a practical vocational and high technological bent, Lancioni, Mezzini, and Marconi in 1993 worked with two people with profound developmental disabilities. One had special computer-aided programme and folder with drawing control programmes to learn choice and choosing activities and reinforcers, the other used two computer-aided programmes but not the control programme. The first subject was very successful at combining choice behavior and constructive activity with the computer-aided programme, but not with the control programme. The second subject learned very rapidly independent activity engagement, but required a relatively long time to develop "meaningful" choice behavior.

In a masterful review of 20 years of choice research, Lancioni, O'Reilly, Emerson (1996), review the literature finding three themes of exploration. They report that studies have been directed at (a) assessing the ability of those people to choose between different options and express preferences that could be used for reinforcement or occupational purposes, (b) building choice opportunities within those people's daily situations, and evaluating the possible effects of choice making on those people's performance and behavior. In the all important area of residential choices, Stancliffe (1997) examine the impact of size of residence in Australia with adults with mental retardation who live in staff-supported community residences housing one to five residents. Significantly individuals living in smaller settings exercised greater choice, even when personal characteristics of individual residents were controlled statistically. Staff presence was confounded with living-unit size. Analyses including both staff presence and living unit size revealed strong effect of staff presence, with more choice displayed in settings with longer periods when no staff members were present. Size effects were less evident once the variability associated with staff presence had been accounted for. Results suggest that both staff presence and living unit size are important predictors of choice. Stancliffe and Abery (1997) suggest in a longitudinal study that choice and deinstitutionalization have been moving forward. Also in 1997, Parsons, Harper, Jensen, and Reid evaluate a protocol involving two types of choice presentations for assessing leisure choice-making skills of seven older adults with severe disabilities. Their results suggest the importance of assessing choice-making skills prior to presenting choice opportunities. Keaney and McKnight (1997) identify a recent revolution in service delivery for persons with developmental disabilities encompassing increased client independence and improved quality of life. This effort reviews and critiques the primary methods of assessing preference and choice for persons with disabilities, including interviews and questionnaires, pictorial presentations, technological apparati, and direct observation. Also examined is the literature on intervention programs designed to enhance choice by giving more choice to clients, teaching choice-making skills, and improving staff member skills regarding choice availability.

By 1998, Lohrmann-O'Rouke and Browder review 18 years of research to provide a synthesis of several procedure variables that may influence the outcome of preference assessment including context, assessment stimuli, selection response, and format. In the same year, Crichton provide a challenging case study of a 50-year-old Scottish man with severe intellectual disability who faced health and mental health challenges after moving to a newly opened community group home. This situation illustrates how problematic it is to find the right balance between restrictive practices and respect for an individual's choice. Miller and Factor (1999)

examined over a 3-year period whether the autonomy of 58 adults living in residences for people with developmental disabilities was associated with their adaptive behavior and community integration. Their results indicated that the opportunities for autonomy in residential settings were related to residents' adaptive behavior and community integration. More opportunities for choice making in residences were associated with greater adaptive behavior, whereas smaller residence size and more resident involvement in decision-making were associated with greater community integration.

Finally, in 1999, Wehmayer and Bolding suggest that the environments, in which people live, learn, work, and play influence many aspects of their lives, including their self-determination. These environments differ in the degree to which they enable people to receive personally designed and individualized supports. In the present study self-determination, autonomy, life choices, and lifestyle satisfaction for adults with mental retardation matched by level of intelligence, age, and gender but differing in type of residence or working environment were examined. Analyses indicated that respondent self-determination, autonomy, and satisfaction as well as opportunities for choice making differed according to settings.

The Target States

Nebraska, South Dakota, and Wyoming are adjacent rural states that share similar characteristics. South Dakota was 32nd, Nebraska was 22nd, and Wyoming 11th for small 1 to 6 person homes (Braddock, Hemp, Parish, & Rizzolo, 2000). Wyoming had 78%, Nebraska had 67%, and South Dakota had 52% of the individuals they serve living in small (1-6 beds) community living settings compared with the national average for small homes of 57%. However, 19% of South Dakota's individuals served residentially lived in residential facilities serving 16 or more people making South Dakota 18th. Nebraska is serving 25% in larger settings, and Wyoming serving 14% in a single state run ICF/MR. Wyoming had no community ICFs/MR. The national average for a state is that 14% of people are served in the larger residential facilities.

The three states ranked in the top sixteen nationally for per capita outlays using the Home and Community-Based Services Waiver (Prouty & Lakin, 2000). Wyoming was 5th, South Dakota was 10th, and Nebraska was 16th. Braddock, Hemp, Parish, & Rizzolo (2000) suggest a similar pattern for the three states in his 1998 total fiscal effort ranking for the three states. Wyoming was 3rd, South Dakota was 15th, and Nebraska was 28th. This is all for the good for the outcome, in the same study, for the rankings for community placements per capita reflect South Dakota as 4th (244 per 100K), Wyoming as 7th (220 per 100K), and Nebraska (155 per 100K) as 18th.

However, the states are not profligate spenders. When the 1999 combination of waiver and ICF/MR average spending per recipient is figured, the ranking of South Dakota is 43rd at $31,842, Nebraska was 34th at $41,288, and Wyoming is 27th at $45,949 (Lakin & Prouty, 1999). The 1999 national average was $48,319 per recipient in the 50 states and District of Columbia.

The three states presently spend more money in their community systems than in their state institutions. Nebraska turned the corner first in 1985, South Dakota followed in 1987, and Wyoming joined in 1992. This turning point came to the nation in 1989 (Braddock, Hemp, Bachelder, & Fujiura, 1995). South Dakota has a higher rate of institutional placement for people with developmental disabilities per 100,000 general population than Wyoming or Nebraska (30.4, 27.4, & 23.6 respectively). The national average is 20.0 in 1997 according to Anderson, Polister, Prouty, Lakin, and Sandlin (1998).

Presently, Nebraska, South Dakota, and Wyoming make extensive use of Federal funds for services for people with developmental disabilities, although Wyoming was the last state to participate in Medicaid beginning in 1990. These partnerships involve 90% of the budgets in the states and include the Home and Community-Based Waivers and ICFs/MR.

Method

The Nebraska, South Dakota and Wyoming Divisions of Developmental Disabilities use the Inventory for Client and Agency Planning (ICAP) (Bruininks, Hill, Weatherman, & Woodcock, 1986). South Dakota has been collecting data with the ICAP since 1986, Wyoming since 1988. Nebraska just began collecting these data last year. The ICAP is a standardized instrument that assesses adaptive and maladaptive functioning. The ICAP form includes demographic data, services received or needed, present placement, and the placement recommended for two years in the future. The ICAP also records recreational and social activities in which the person participated in the 30 days before the completion of the form. It also records specific factors that may limit those activities.

In 1988, ICAP data were collected for 817 people in Wyoming, and 2,017 in South Dakota. In April 2000, data were assembled for 1,633 consumers of services/supports in Wyoming, and 2,440 people from South Dakota. Nebraska also contributed their current ICAP data, with 2,961 records.

For 1998, Current Residence (ICAP, field F1) was compared to the Recommended residence (field F2); and "Current Formal Daytime Activity" (ICAP G1) was compared to the Recommended Daytime Program (G2). The percentages of people who had each of the Social and Leisure Activities listed in ICAP item I1 were also calculated. Finally, the percentages of people who had each of the "Factors limiting social activities," in subsection I2 of the ICAP, were tabulated.

The same calculations for each state were made for the 2000 data; and contrasted to the 1988 findings for South Dakota and Wyoming. Nebraska's 1999 data were also added to the 2000 current vs. recommended contrasts for both residential and day programs. Finally, data from all three states were combined to give an overall view of residential and daytime service/support utilization in 2000.

Results

As recommendations change, they present a moving target for the service delivery system. Whether or not people are living, learning, working, and playing in their recommended setting can be considered a desired outcome. Since these recommendations are steadily changing, it becomes a challenge to assure that the maximum number of people attains those outcomes. Actual placements in those recommended settings continually lag behind the recommendations. Trends in South Dakota and Wyoming from 1988 to 2000 are shown in Figures 1 and 2 for Residential Placements, and Figures 3-4 for Daytime Programs. Figures 5 and 6 examine 12-year changes in Social and Leisure Activities in South Dakota and Wyoming; while Figures 7-8 present the trends in the reported factors, which limit those activities. Current data for all three states are compared in Figure 9 (Residential), and Figure 10 (Day Programs). Finally, data from all three states are summarized in Figures 11 and 12, to give an overall perspective of current placements and recommendations.

Residential Placement Recommendations

Figures 1 and 2 show the changes in recommendations, and subsequent residential placements over the past 12 years, in South Dakota, and Wyoming, respectively. In 1988, both states had significantly more people in their state institutions than recommended by even institutional staff. By 2000, the actual numbers of institutional residents were substantially below the 1988 recommended numbers. The 2000 recommended numbers are still slightly below the current numbers. Group homes grew significantly in Wyoming, but appear to be holding steady in South Dakota. While foster home placements grew in Wyoming, they were declining in South Dakota. The two states appear to have taken different tacks in the development of alternative services. Wyoming has seen very strong expansion in supporting people who are living in their family homes. Many of these folks are children. On the other hand, South Dakota has focused most of its expansion into supported living for adults. The "moving target" concept is nicely illustrated by this growth of supported living. In 1988, South Dakota had only 154 people receiving supported living; although this was the recommended situation for 287 people. By 2000, the numbers of people receiving supported living had risen to 616; but it still lagged behind the recommended number, which had now had increased to 673.

Figure 9 shows these same data from 2000 in relation to the most current data from Nebraska. Like the other two states, Nebraska's recommended numbers show a 28% decrease in the institutional population, and a corresponding rise in the group home population. The other two residential settings, where substantial increases are recommended in Nebraska, are supported living and semi-independent living, e.g. "supervised apartments." Figure 11a summarizes these general trends. Overall, in 1988 South Dakota had 66% living in their recommended settings; and Wyoming, 69%. In 2000, South Dakota had increased to 88%, and Wyoming to 90%. Nebraska was at 82% in 1999.

Vocational or Day Treatment Recommendations

Figures 3 and 4 show similar trends for South Dakota and Wyoming; but for Daytime Programs. A small, but noteworthy, trend is the appearance of a number of people with "no formal daytime program." Although the decline of the institutional population in Wyoming saw a corresponding increase in the numbers of people spending their days in sheltered workshops (this denotes all facility-based daytime programs in the community, regardless of wages paid.); the sheltered workshop population in South Dakota is virtually unchanged over this 12-year period. South Dakota did experience a proportionately larger growth in supported employment during this time. Again, the "moving target" concept is well illustrated by South Dakota's supported employment population. In 1988, there were only 101 people in supported employment, substantially behind the recommended number of 374. By 2000, although 546 people were receiving supported employment, this number was even farther behind the recommended level of 785. Wyoming's dramatic growth in the "school" numbers reflects the corresponding growth of its HCBS Child Waiver.

Figure 10 adds Nebraska to the previously reported 2000 South Dakota and Wyoming findings. The most notable finding: All three states recommend fewer individuals in institutions and sheltered work in the future; but more in supervised/supported job placements, and in competitive employment. This finding is reiterated in the three-state summary in Figure 11b. Decreases in sheltered workshops can be expected to be offset by growth in competitive and supported employment.

Overall, in 1988 South Dakota had 63% of their people working in the recommended setting, and Wyoming had 55%. By 2000, South Dakota's percentage had grown to 78% and Wyoming's to 83%. Nebraska was a 77% at the end of 1999.

Social Activities and Identified Barriers

Figures 5a-f show the percentage of those participating in various social activities in the last month in South Dakota; and Figures 6a-f show those activities in Wyoming. Trends were in the desired direction. The percentage of those having telephone contact with family or friends increased and "visited with family" grew. The percentage of those in both states having visited friends outside the residence generally increased. Most of the people served in both states went out to eat or shopping in 2000 and this remains one of the most popular reported social outings. The percentage of those reporting recreational or social activities outside the home grew, as did the percentage of those in both states participating in hobbies or leisure activities.

The three states showed a very high percentage of the people served enjoyed social activities. The overall percentage of people facing or reporting social barriers in South Dakota and was lower than in Wyoming. Figures 7 and 8 refer to

identified barriers in South Dakota and Wyoming, respectively. Having "no one to accompany them" was a problem in both states; and curiously for 2000, the highest percentage was reported for people living with their families – 41% for Wyoming. Similarly, transportation was a barrier reported more often in Wyoming but fairly rare and unreported in South Dakota though both institutions improved. Lack of interest was reported more often in Wyoming but sometimes it emerged a bit in South Dakota with both institutions showing a small improvement. Money was a greater limitation reported for those in Wyoming than in South Dakota where the problem was slight. The pattern for health limitations was similar to that for money. Wyoming reported health limitations to activities with health problems showing up in all residential settings in the Cowboy State. In South Dakota health was rarely reported as a barrier in 2000. In 2000 approximately a few people in South Dakota and many more people in Wyoming reported behavior problems as a barrier to social activities. This was true in institutional settings in South Dakota and in one half to one third of all living settings in Wyoming. South Dakota often reports fewer barriers and this portion of the ICAP may not really be recorded as carefully in that state. Interestingly Wyoming, where services and supports have increased the most, may generally be overstating reported barriers for many people for reasons that are not yet apparent. Another general trait of these barriers appears to be that lack of money and transportation is most common among those people living independently, or with supports.

Discussion and Conclusions

Placement recommendations reflect more independent and supported living, more individuals staying with their families, more individuals in supported work or competitive employment, and decreased reliance on institutional placements. South Dakota leads Wyoming and Nebraska in the rate of people in community living who are independent with support or live in supervised apartments, and has greater expectations for future placements.

There is a marked increase in Wyoming's rate for persons in the various day treatments like work activities (prevocational), or day habilitation that are included under the category of sheltered workshop. This is most likely a result from Wyoming's implementation of a Home and Community Based Services Waiver in 1991, which funds the prevocational and day habilitation services. Additionally, more individuals with significant and multiple disabilities moved from the Wyoming State Training School to the community during the interval.

Between 1988 and 2000, Wyoming increased, in most settings, reported barriers to community participation. The three states increased the percentage of persons in their recommended day treatment and residential settings. Throughout the period, South Dakota had a smaller percentage of its clientele identified as facing barriers than Wyoming. By 2000, Wyoming showed more people reporting problems like transportation and having no one to accompany the person. However, the percentage of persons reporting lack of interest, money, or behavior problems as barriers to participation also increased in South Dakota. It may be that increased

services and supports also increase people's awareness of barriers making their reduction a moving target.

More individuals in both states are living, learning, playing, and working in the settings they choose, although the percentage increase during the interval was greater for Wyoming than South Dakota. The South Dakota system had a longer service history and had a stable package of funding during the interval. South Dakota also had more time and money invested in the more restrictive settings. The 35 ICFs/MR and large group homes were common during that state's service system growth period in the 1970s and 1980s. These settings such as large (7-15 people) group homes or work activity settings were also dominant in Wyoming in the early 1980s. The influx of federal funds and the expansion of services allowed Wyoming to develop smaller community living settings. State service systems for people with developmental disabilities seem rapidly to set like concrete in the form common to their developmental era. It is not easy to transform these mortgaged and invested systems to allow newer work, learning, playing, and living sites emerge. The moving target of recommended sites also changes in a cyclical manner. As client choice becomes a more salient factor, recommendations tend to change in the direction of increased integration and independence. South Dakota hit a high point in the 1987 with 87% of its people getting the program they wanted and is approaching that high with the current 83% rate. Wyoming reached a new all time high of 83-90% of its people getting the program(s) they wanted in 2000. It is notable that the two states often reach similar ceilings and floors. Nebraska has a very respectable 77-82% rate of people getting what they want for a program in 1999.

Nationally, changes in the size of residential facilities have moved from an average of 22.5 people in 1977 (Lakin, White, Hill, Bruininks, & Wright, 1990) to 7.4 in 1988. This has decreased to 3.5 in 1997 (Anderson, Polister, Prouty, & Lakin, 1998). The smaller number of people per dwelling may have allowed increased experiences in the community. In 1997, Nebraska has a low average of 1.7 average, South Dakota's average number of residents per setting of 2.4, and Wyoming's 2.1 may have allowed the three states to increase social activities and program choice while working to reduce barriers.

The three states have made significant fiscal commitments. Money matters, it shapes the system. Comparing Federal HCBS expenditures in 1988 with 1998, Wyoming used 24 million dollars more. In FY1998 from Federal HCBS expenditures, South Dakota is using 27 million dollars and Nebraska is using 41 million dollars on supports and services for individuals served (Braddock, Hemp, Parish, & Rizzolo, 2000). During the last fifteen years the three states struggled and succeeded in maintaining and improving supports and services. The three states, as do all states, face periodic variations in state funding.

The methodology presented here provides a way to compare the three state systems' performance. How well have the service and support systems reduced social barriers, increased social activities, and helped the person served obtain his or her desired settings to work, learn, play, and live? This paper suggests that improvements may cycle over the years and be subject to the ebb and flow of public

funding and national service trends. Forward progress will require considerable vigilance and careful monitoring of whether we are having fun yet. Nebraska, South Dakota and Wyoming have made progress in these areas. These states continue carefully to aim at the moving target of social change, professional advice, and of individual and interdisciplinary team choice.

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Figure 1. South Dakota Residential Trends

Figure 1a. 1988 SoDak Current Residence (F1) by Recommended (F2)

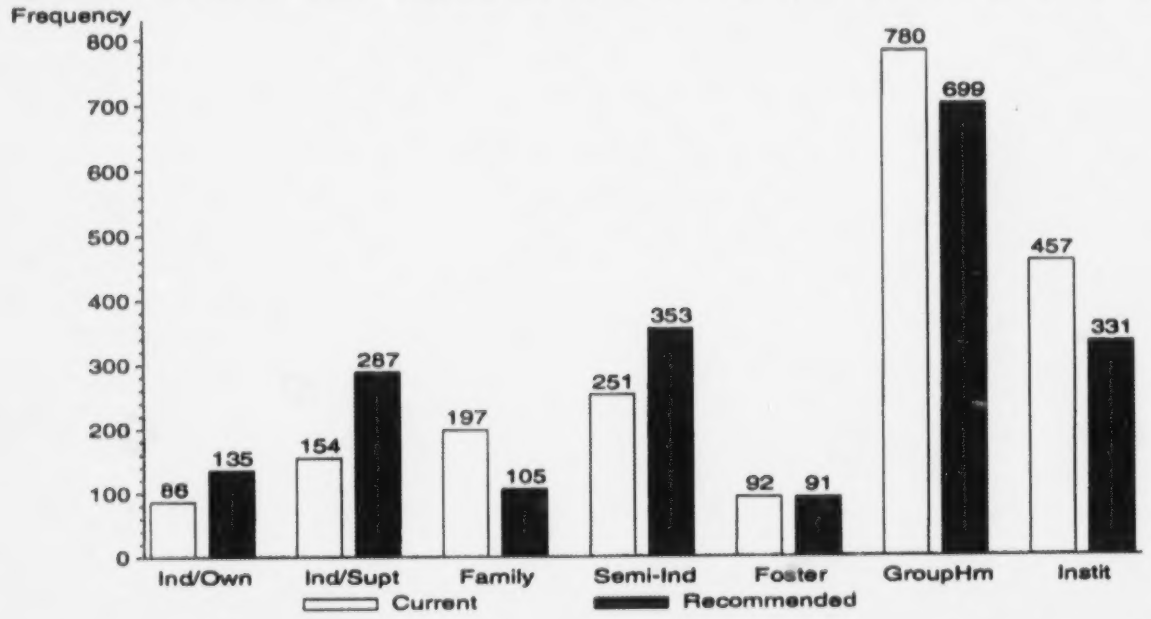
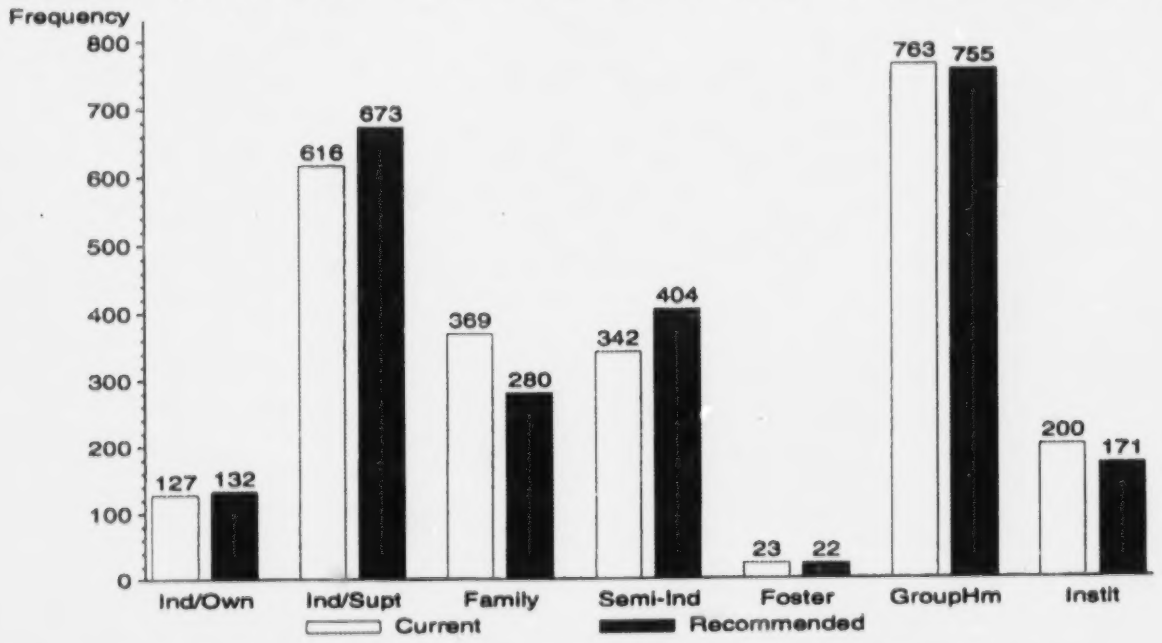


Figure 1b. 2000 SoDak Current Residence (F1) by Recommended (F2)



Note: This time period encompasses the closure of the state-operated facility at Custer.

Figure 2. Wyoming Residential Trends

Figure 2a. 1988 Wyoming Current Residence (F1) by Recommended (F2)

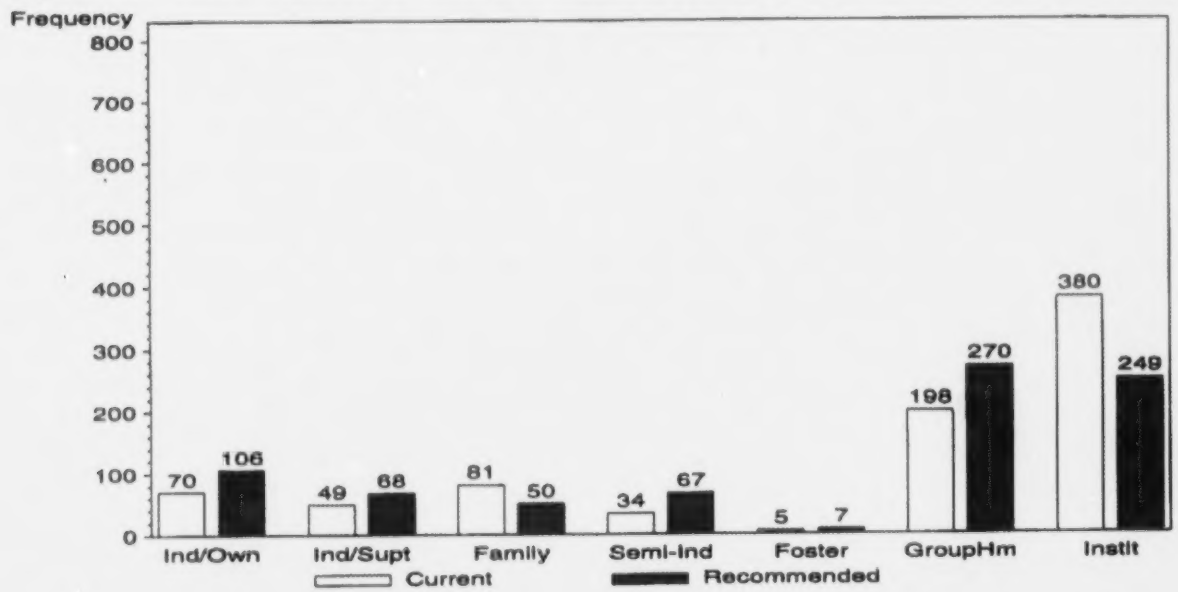
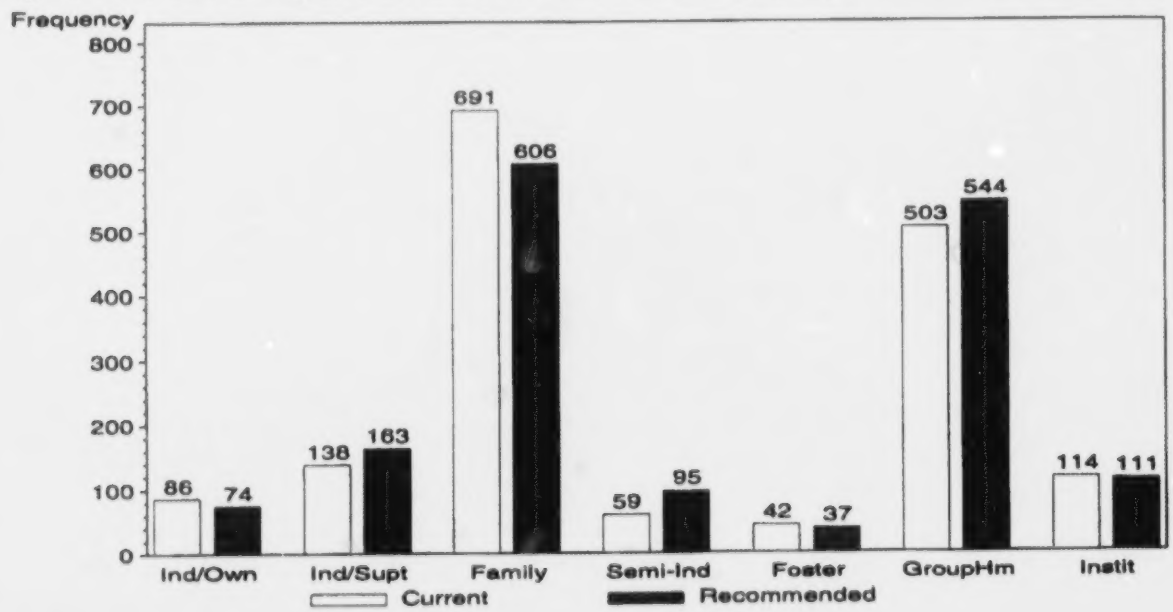


Figure 2b. 2000 Wyoming Current Residence (F1) by Recommended (F2)



Note: Time frame includes Wyoming's lawsuit.

Figure 3. South Dakota Daytime Program Trends

Figure 3a. 1988 SoDak Current Day Program (G1) by Recommended (G2)

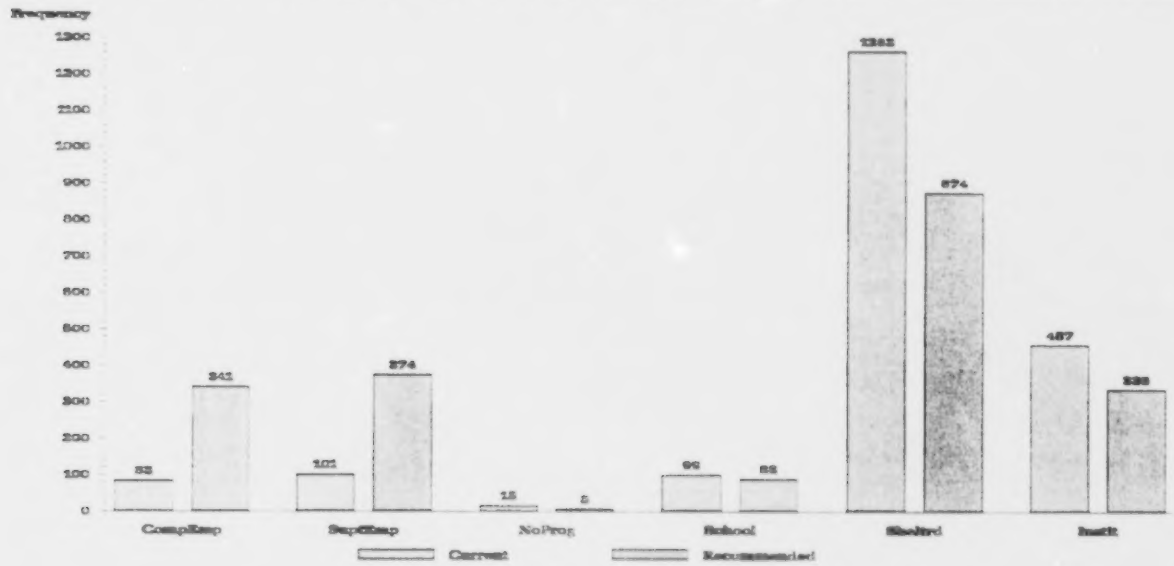
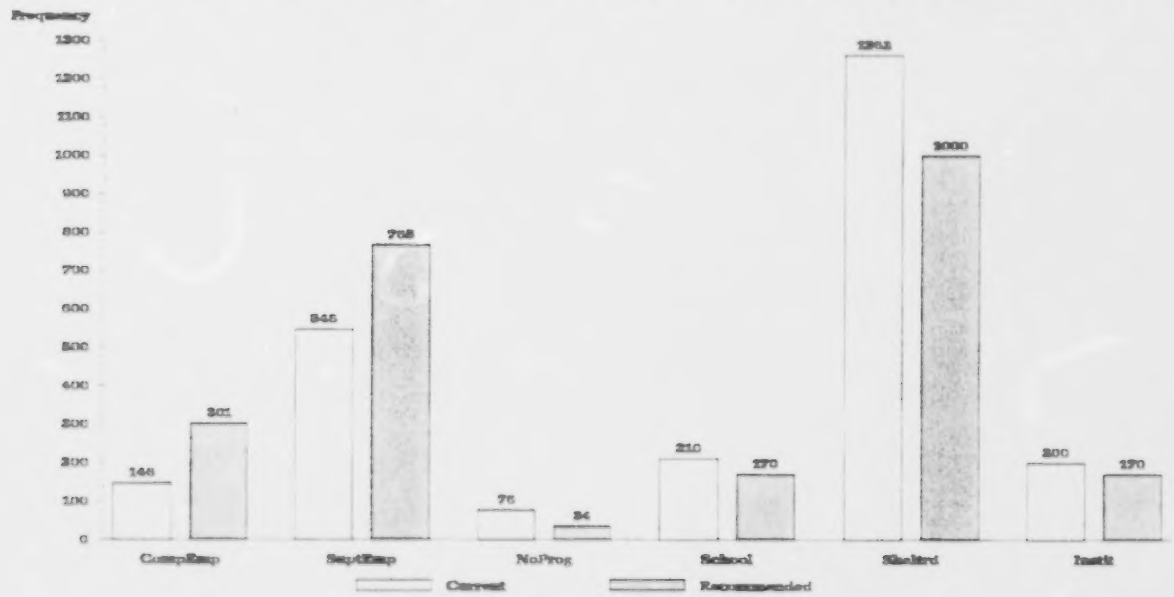


Figure 3b. 2000 SoDak Current Day Program (G1) by Recommended (G2)



Note: "Sheltrd," i.e. Sheltered Workshop includes all community facility-based entries in ICAP field G: Day activity center (5), Work activity center (6), and Sheltered workshop (7).

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Figure 4. Wyoming Daytime Program Trends

Figure 4a. 1988 Wyoming Current Day Program (G1) by Recommended (G2)

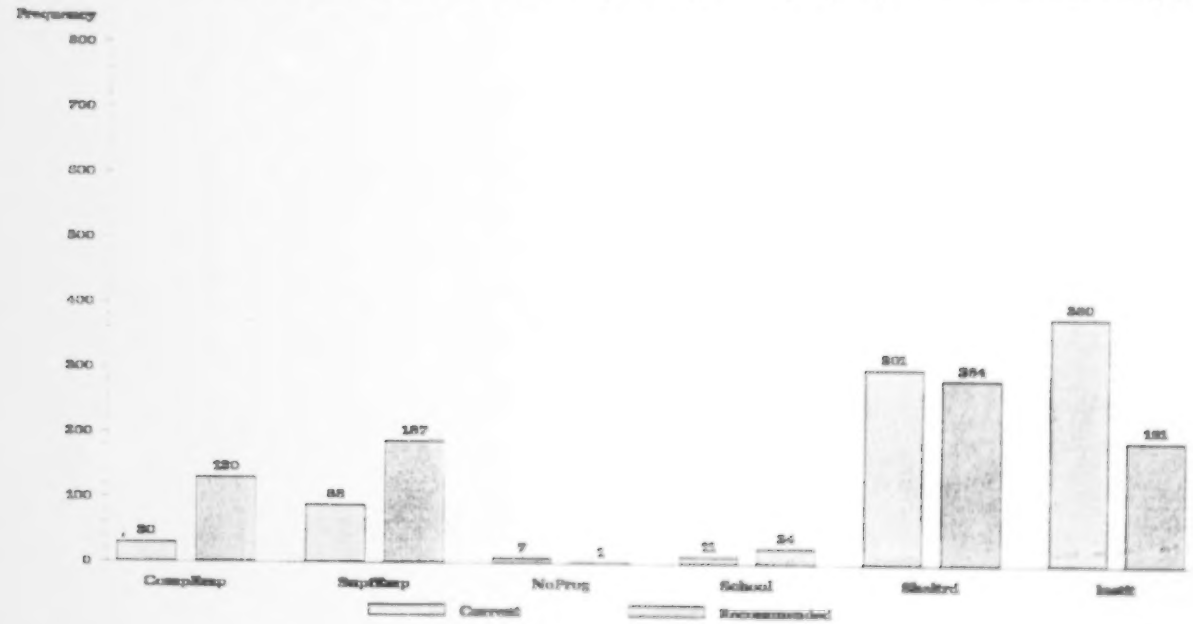
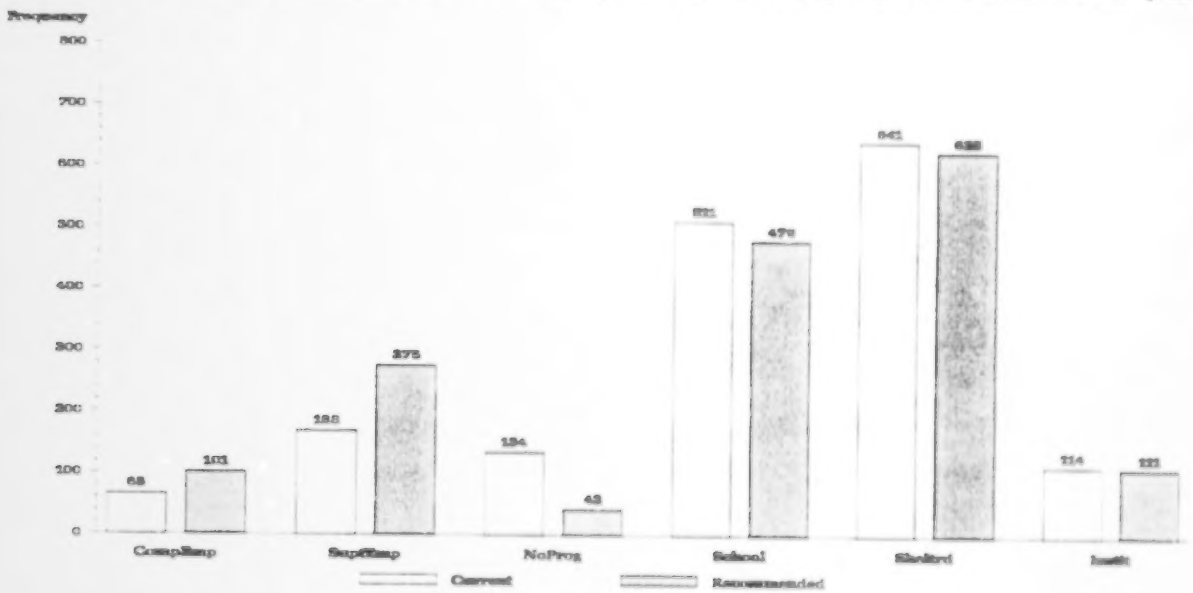


Figure 4b. 2000 Wyoming Current Day Program (G1) by Recommended (G2)



Note: "Sheltrd," i.e. Sheltered Workshop includes all community facility-based entries in ICAP field G: Day activity center (5), Work activity center (6), and Sheltered workshop (7).

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Figure 5. South Dakota Social and Leisure Activities

Figure 5a. Phoned Family or Friends?

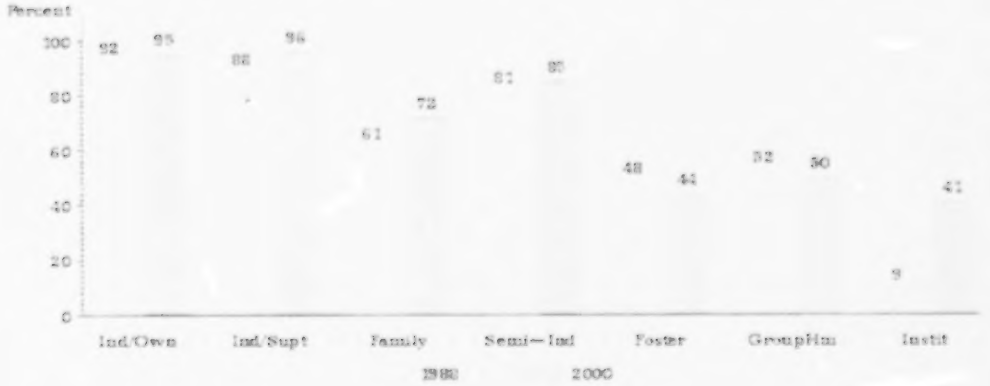

Figure 5b. Visited with Family?

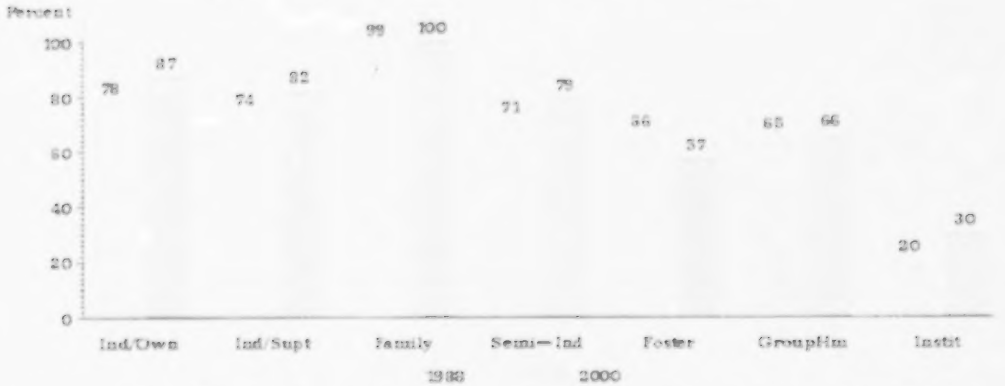

Figure 5c. Visited with Friends from Outside Residence?

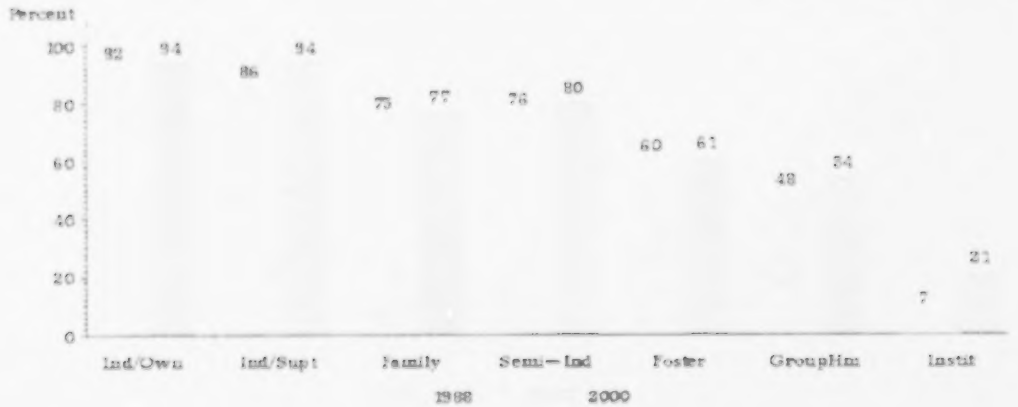

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Figure 5d. Shopping or Out to Eat?

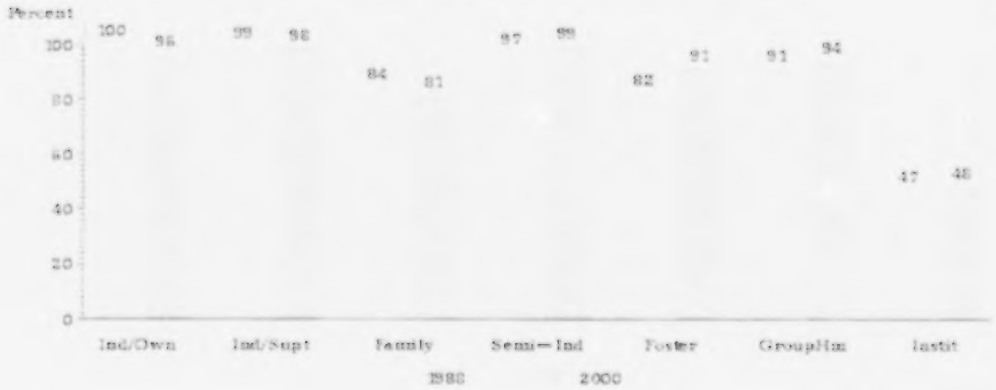

Figure 5e. Outside Social/Recreational Activity?

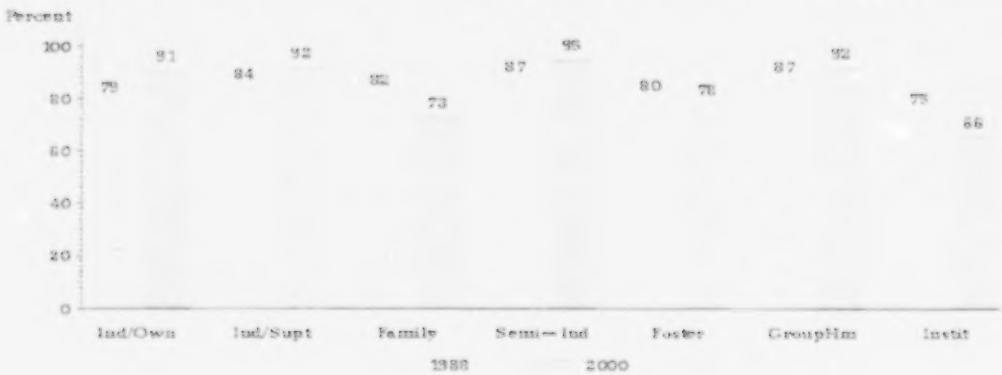

Figure 5f. Hobby or Personal Leisure Activity?

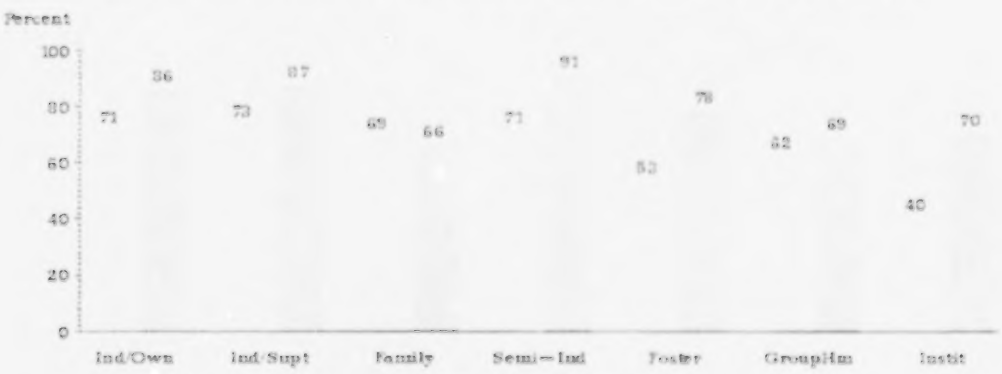

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Figure 6a. Phoned Family or Friends?

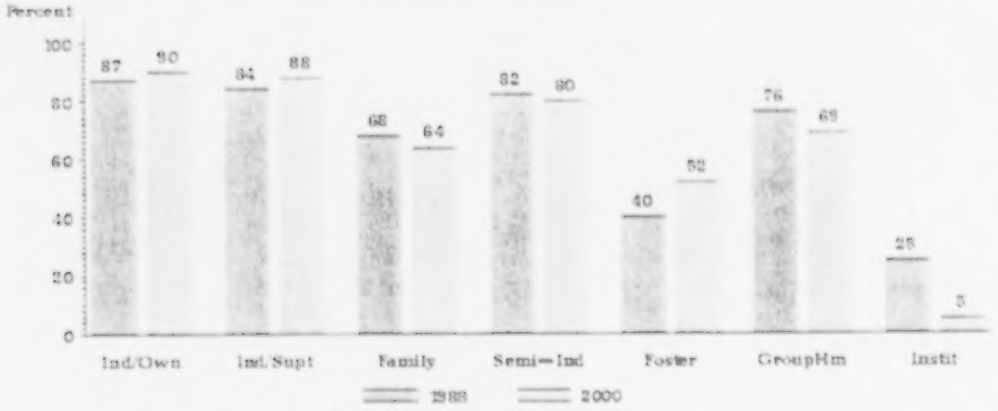

Figure 6b. Visited with Family?

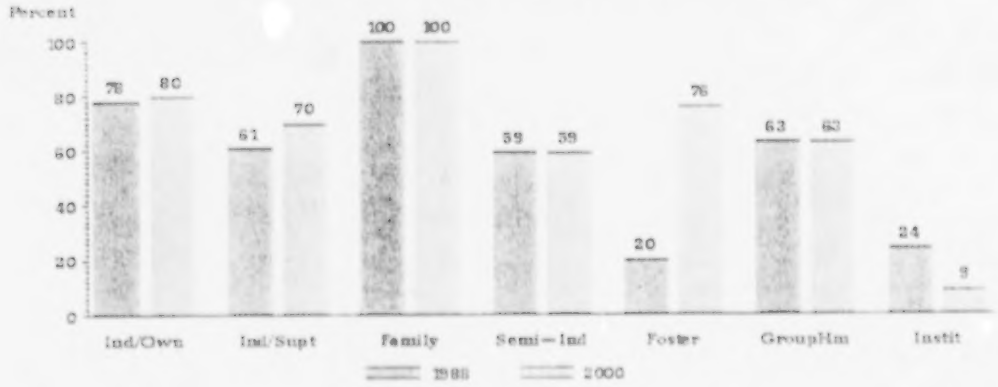

Figure 6c. Visited with Friends from Outside Residence?

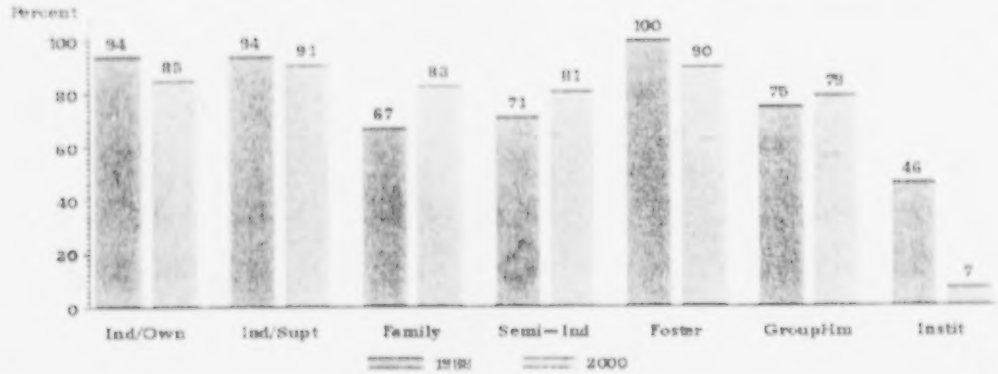

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Figure 6. Wyoming Social and Leisure Activities

Figure 6d. Shopping or Out to Eat?

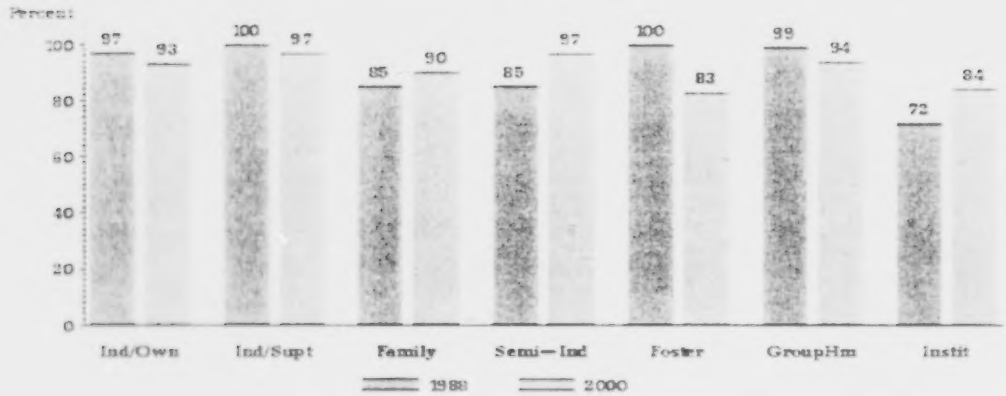

Figure 6e. Outside Social/Recreational Activity?

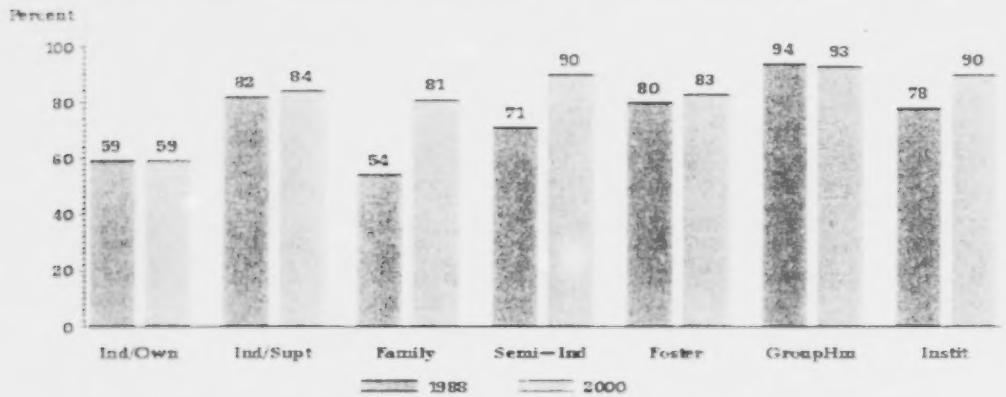

Figure 6f. Hobby or Personal Leisure Activity?

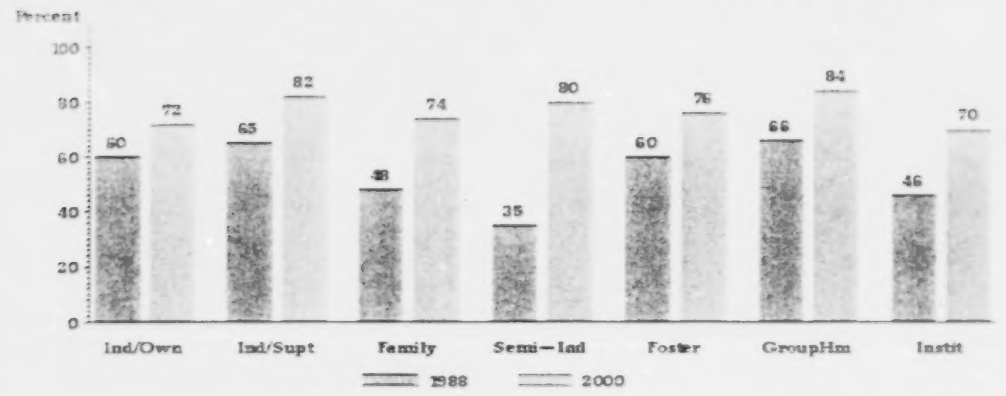

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Figure 7a. Lack of Interest

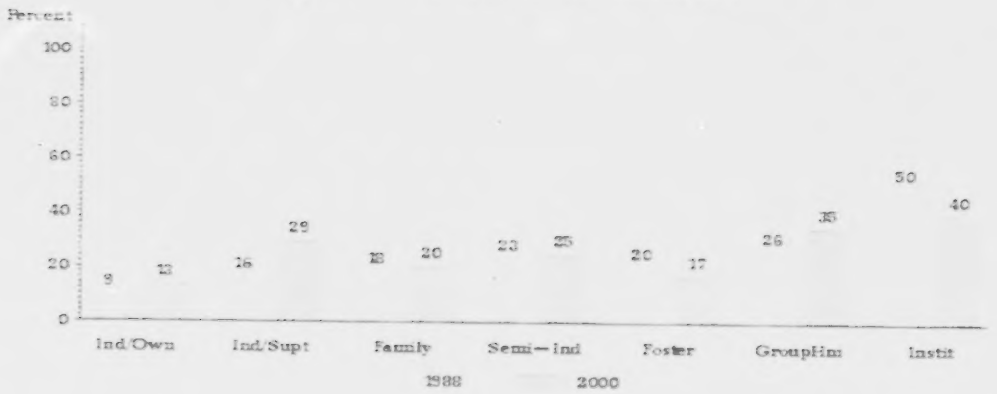

Figure 7b. No One to Accompany

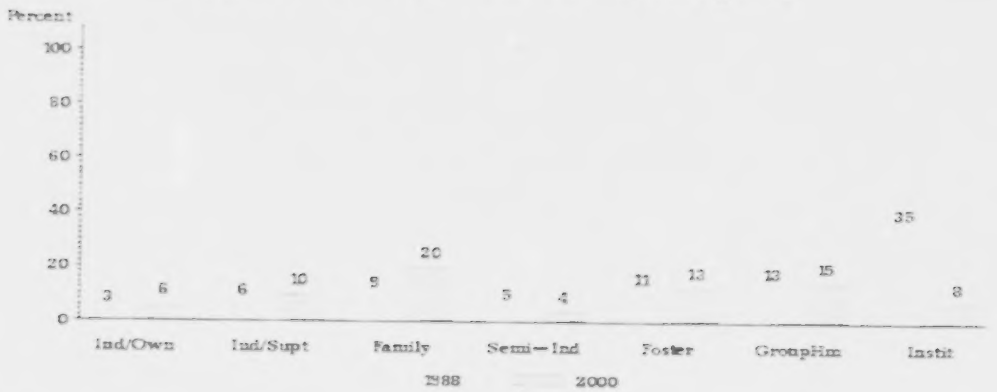

Figure 7c. Lack of Transportation

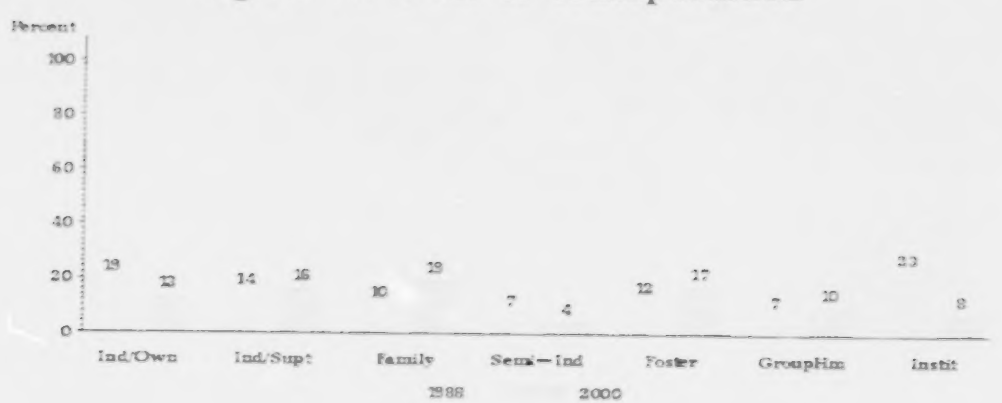

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Figure 7d. Lack of Money

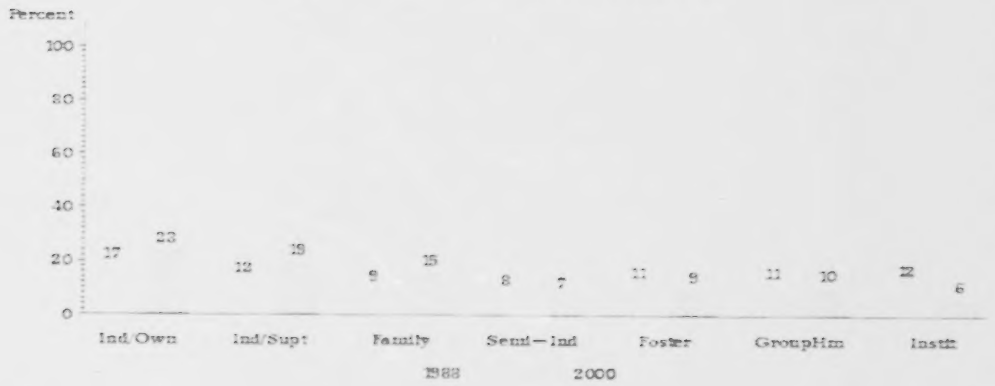

Figure 7e. Health Problem

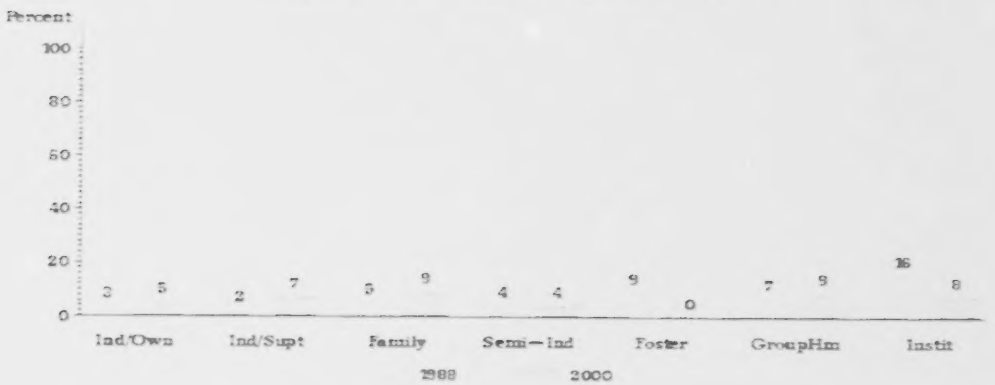

Figure 7f. Behavior Problem

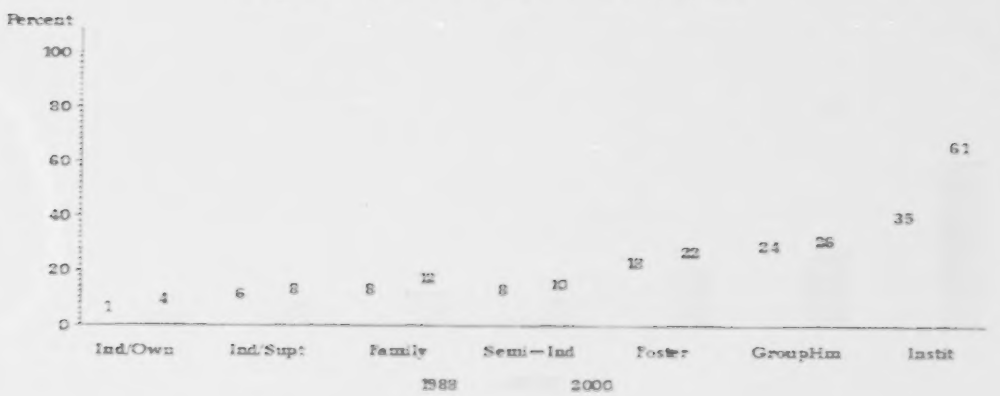

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Figure 8. Wyoming's Factors Limiting Social Activities

Figure 8a. Lack of Interest

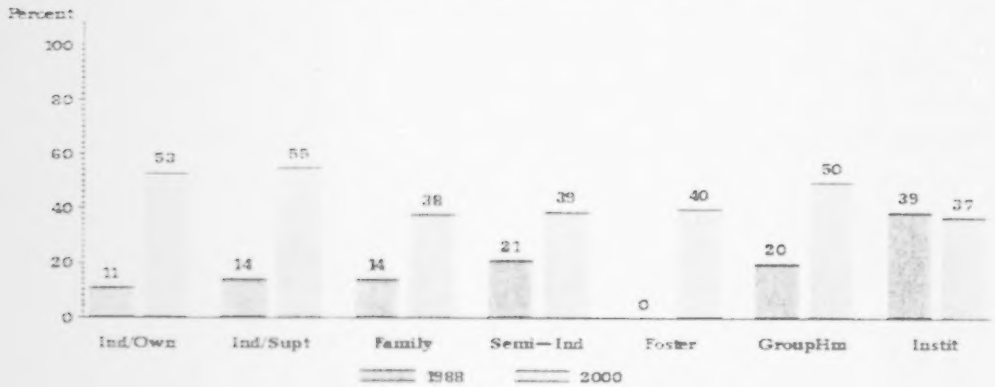

Figure 8b. No One to Accompany

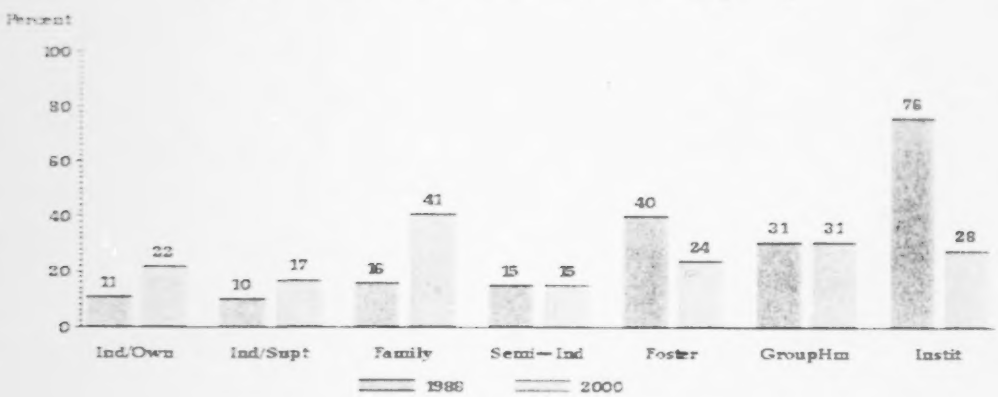

Figure 8c. Lack of Transportation

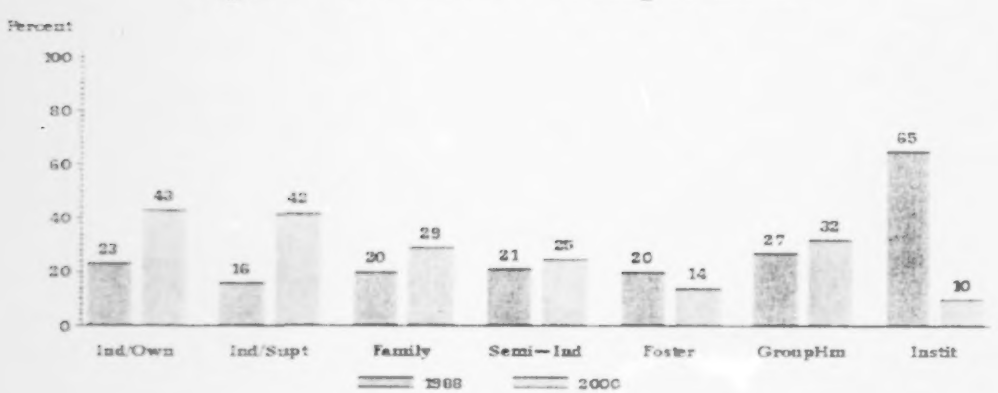

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Figure 8d. Lack of Money

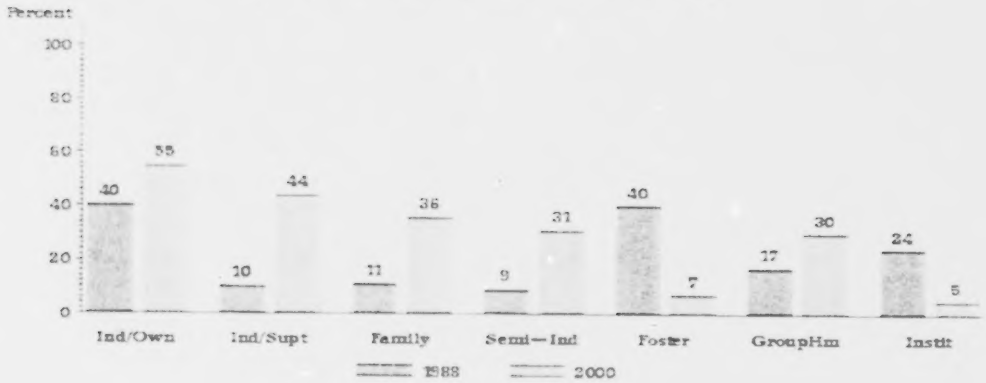

Figure 8e. Health Problem

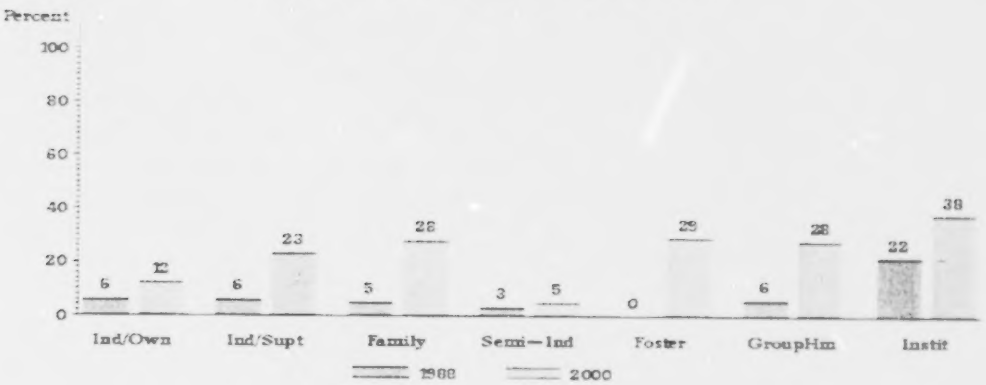

Figure 8f. Behavior Problem

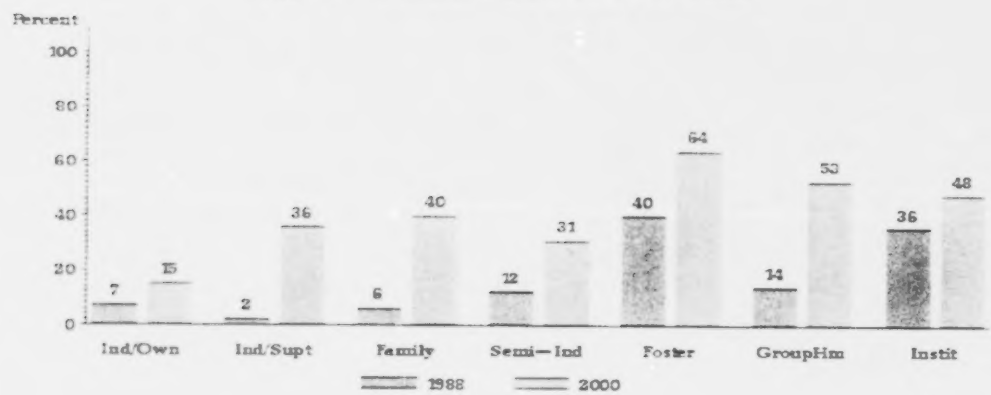

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Figure 9a. 1999 Nebraska Current Residence (F1) by Recommended (F2

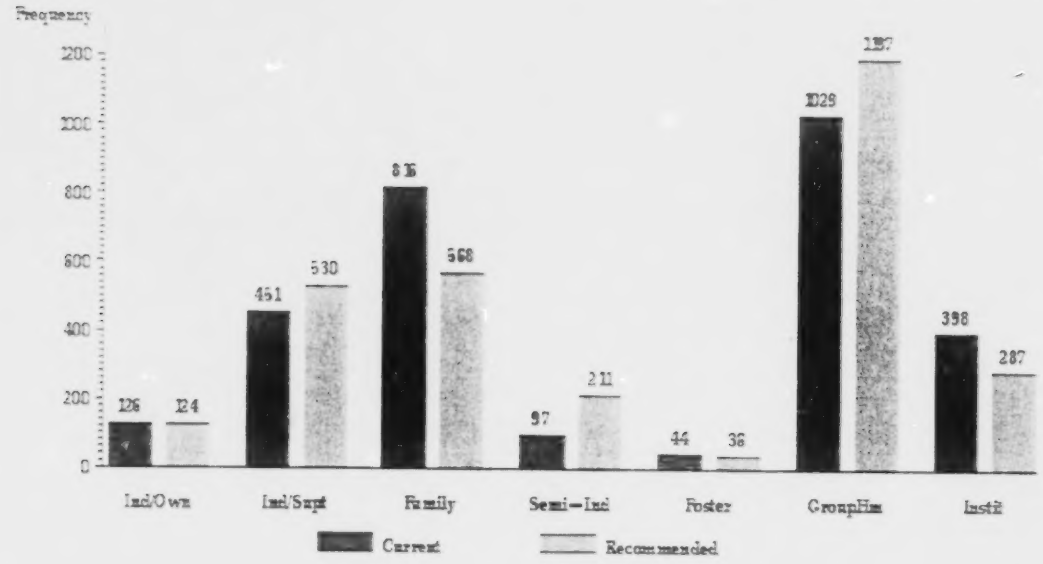

Figure 9b. 2000 SoDak Current Residence (F1) by Recommended (F2

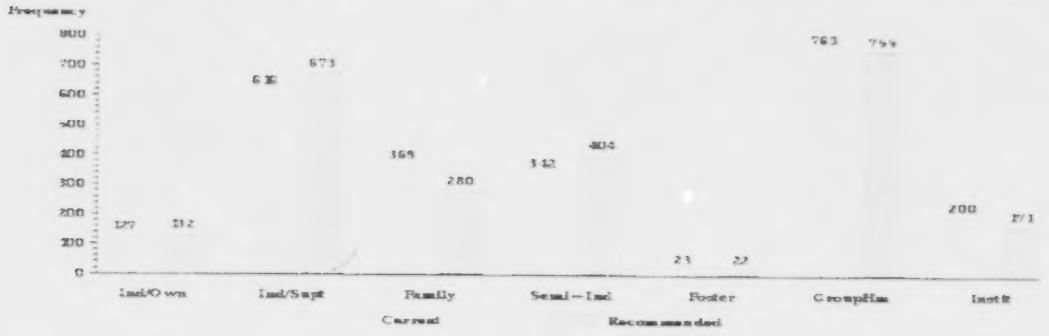

Figure 9c. 2000 Wyoming Current Residence (F1) by Recommended (F2

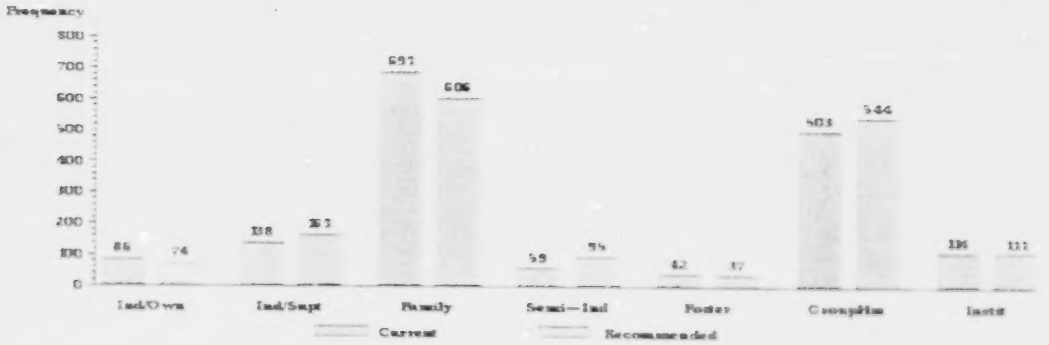

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Figure 10. Current Day Program by Recommended

Figure 10a. 1999 Nebraska Current Day Program (G1) by Recommended (G2

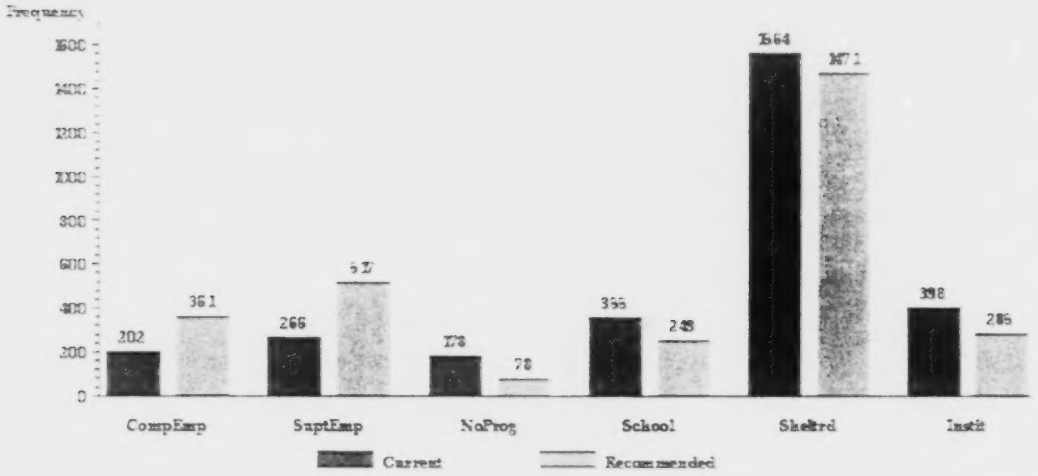

Figure 10b. 2000 SoDak Current Day Program (G1) by Recommended (G2)

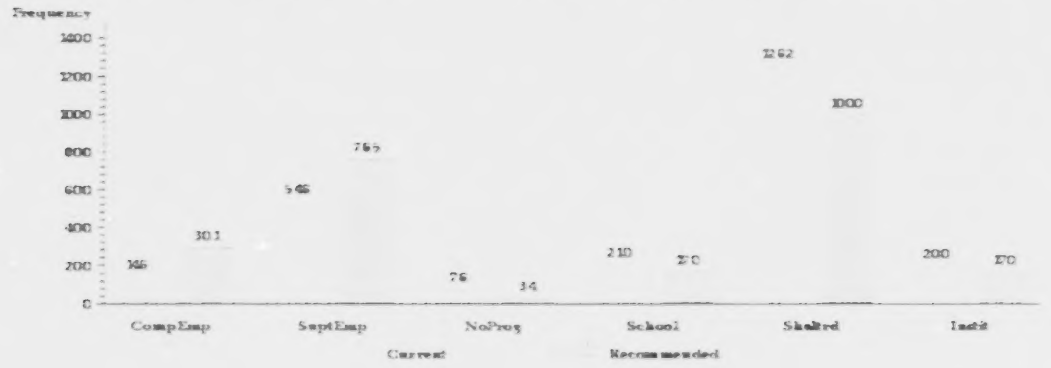

Figure 10c. 2000 Wyoming Current Day Program (G1) by Recommended (G2)

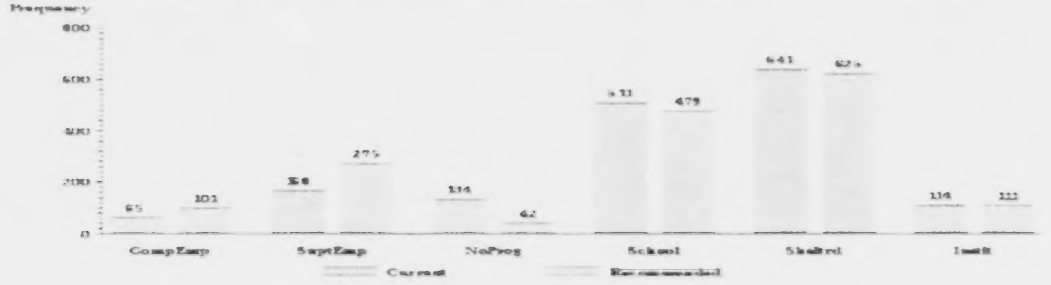

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Figure 11. Combined Data (NE, SD & WY)

Figure 11a. Current Residence (F1) by Recommended (F2)

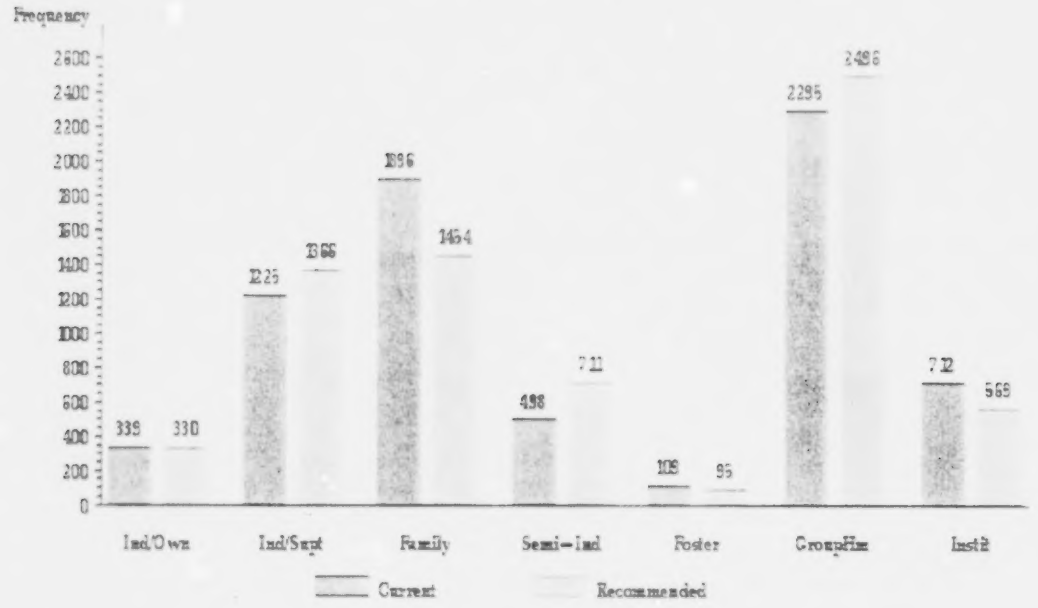

Figure 11b. Current Day Program (G1) by Recommended (G2)